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Bittersweet: A qualitative exploration of mothers' experiences of raising a single surviving twin.

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Abstract

Loss of a child from a multiple birth pregnancy is not uncommon yet the idiographic experience of parents who have lost a single twin from a multiple birth pregnancy is underexplored. This novel study sought to explore the experiences of mothers bereaved after loss of a twin from a multiple birth pregnancy, focusing on the dual challenges of parenting and grieving. Eighteen mothers at least 12 months post loss were recruited from a private UK based Facebook page dedicated to supporting parents after loss from a multiple birth. Eligible mothers completed an independent qualitative open-ended survey to explore maternal experiences of loss. Data were analysed using Thematic Analysis. Findings represented a sense of duality for participants, with mothers experiencing conflict between roles and identities as well as the nature of their loss. Key themes identified include 'Narrating a story of family and loss', 'Finding a place for the twins within the family' and 'A changing sense of self'. Findings fit with theoretical conceptualisations of bereavement that acknowledge retaining relationships with the deceased. Practically, suggestions for supporting mothers to identify stock answers to often asked questions about family make up were suggested.

Introduction

Recent figures have identified high infant mortality rates in the UK compared with other European countries (Office for National Statistics, 2013). Multiple birth pregnancies are especially risky, demonstrating almost five times higher infant mortality rates compared with singleton births (Office for National Statistics, 2015). Despite increased infant mortality, research has primarily focused on loss of a singleton in terms of parental experience and support needs (Lisy, Peters, Riitano, Jordan & Aromataris, 2016; Flenady et al. 2014). Studies have most often explored the experiences of mothers after a stillbirth or neonatal death, identifying high levels of psychological distress and isolation post loss (Cacciatore, 2013; Burden et al., 2016). Whilst such studies inform parental support needs after loss of a singleton, they are unable to address the complexity associated with parental experiences after loss from a multiple birth (Richards, Graham, Embleton, Campbell & Rankin, 2015). Studies focusing on parents who have been bereaved from a multiple birth have typically used idiographic methods to explore parental experiences in particular situations such as caring for a surviving twin in a neonatal environment (Richards et al., 2015) or parent support needs post loss (Swanson, Kane, Pearsall-Jones, Swanson & Croft, 2009). Whilst these studies have furthered understanding of parental needs in specific situations, no studies have examined how parents who experience the loss of a single twin manage the dual challenges of parenting and grieving. Addressing this particular knowledge gap, this study presents an in-depth qualitative analysis of the experiences of eighteen mothers who have lost a single twin at or around the time of birth, focusing specifically on experiences of parenting and grieving for their twins.

Methods

Design

Mothers who had lost a single twin from a multiple birth pregnancy completed a qualitative open-ended survey (Clarke & Smith, 2015)

Ethics

The study received ethical approval from the University of Bath.

Participants

Participants were recruited from a private UK Facebook page dedicated to supporting parents after loss from a multiple birth. Eligibility criteria included having access to the online bereavement support page and being a parent who had lost a single twin at least 12 months prior to study participation. Individuals who had lost more than one child from a multiple birth pregnancy were excluded. Participant median age was 31-40 years (range 21-50), with a median time since loss of 48-59 months (range 1-20 years).

Data collection

A recruitment message was posted on an online bereavement support page. Interested participants (N=37) contacted the researchers who emailed them an information sheet, survey questions and a survey link. Participants were required to endorse informed consent statements prior to survey completion. Eighteen participants completed the survey.

Qualitative survey

The survey comprised five open-ended questions and demographic questions. Bereaved parents and members of bereavement organisations contributed to question development.

Table 1 near here

Analyses

Data for each question were transferred into a Word document and anonymised. Data were analysed using inductive Thematic Analysis (Braun & Clarke, 2006).

Authors familiarised themselves with each question specific document (Braun & Clarke, 2006), and developed codes to describe phenomena before identifying themes across the wider data set. To establish trustworthiness and credibility of data, analyses were conducted independently by authors, with themes discussed over multiple meetings to reach consensus. Themes were refined to ensure they represented the data and a varied range of participant accounts (Shenton, 2004).

Results

An overarching theme of duality was identified; not just in terms of how parents viewed their often competing roles and identities but also in the sense of the duality of the loss (their loss as a parent and loss for the surviving twin). Three main themes (see Figure 1) were identified: ‘Narrating a story of family and loss’, ‘Finding a place for the twins within the family’ and ‘A changing sense of self’. Pseudonyms have been used throughout.

Figure 1 near here

Narrating a story of family and loss

This theme reflects the difficulties that mothers' experienced as they sought ways that felt acceptable to them to talk about their family. Specifically, mothers found it difficult to know whether and if so, how, to include their deceased child in conversations. Such decisions were dependent on the situation, the identity of the 'other person' and the mother's state of vulnerability.

If a stranger asks how many children I have, I only say 4 [...] Even if they bring up twins or say for example, that they have twins, I say nothing, though it hurts a lot. BUT if an acquaintance asks, I will usually say I have 4, but I have had 5 children. I tell them that I lost one of my twin sons shortly after birth. I find this works best for me as I am not exposing myself emotionally to a random stranger who I will likely never see again. (Jessica).

This process was especially difficult for mothers at the start of their bereavement journey as they sought to avoid anxiety associated with answering everyday questions about family membership:

I always answer that I have one child. For the first year or so the guilt I felt about this was awful. I felt like I was denying my son's existence. [. . .] With time I still answer the same way, however I feel very different about my answer. I do not know these people, therefore I do not feel comfortable sharing with them my most private matters. I am not denying his existence, I feel I am protecting his memory and keeping him safe, as well as keeping myself safe (Hayley).

As Hayley described, mothers who chose to keep quiet typically began to appreciate that were protecting their child's memory rather than denying their existence. Contrastingly, other participants developed 'stock answers' that they could draw from, depending on how they were

feeling at any specific time. Having ready answers was less draining than having to think about what to say:

My usual response is "I have twins, a boy and a girl, but my little boy passed away" or other times I might say "I have a surviving twin". It very much depends on my own emotional state at the time of being asked (Angela).

Deciding how and whether to talk about their lost child required the mothers to recognise that they had to manage their feelings, *as well as* the sometimes unpredictable responses of others.

I find that people don't know what to say. The conversation either gets very serious [...] or people will say things that just make me angry and upset [. . .]. Talking about Isobel is always a risk that needs to be calculated, will it hurt or help? (Emily).

In contrast, others mothers like Kelly, made the decision to confront the unease surrounding the topic of child death by *always* speaking, regardless of the reactions of others:

I always talk about both my girls to friends and colleagues whether they want to hear it or not. I will not stay quiet or pretend she doesn't exist just to make people feel more comfortable. (Kelly).

Finding a place for the twins within the family

This theme was marked by the tensions experienced as the mothers navigated the path of maintaining a position for the lost child within the family, whilst simultaneously celebrating the development of the living child. Jane noted 'seeing my survivor blooming and developing was a constant reminder of my loss'. This tension grew as mothers tried to find a place for the deceased child within the family, wanting to avoid a future revelatory moment when the surviving twin learned about their deceased sibling. To combat this, mothers focused on being honest with their surviving twin and other children, from an early age:

We have always talked openly from the very beginning about his brother who died. We didn't sugar coat it or give him special names like Angel Brother. He died, the doctors tried their hardest to save him but it wasn't to be. (Rebecca).

In time, siblings' questions became increasingly difficult to answer.

As she has got older her questions have somewhat matured. She asks things like how did her brother get to heaven "Did someone open the window and did he fly up to heaven" it breaks my heart having to have such conversations. (Kerry).

In order to minimise distress in their surviving children, mothers carefully balanced the extent to which they talked about the deceased twin. 'I don't talk about his brother all the time as I want him to be his own person and not carry the burden that I bear. I do not want him to feel guilty that he lived'. (Heather).

As this sense of burden where one twin lives and one dies, is unique, it was particularly difficult when families celebrated milestones which represented reminders of both loss and achievement.

Milestones and 'firsts' are difficult and emotional e.g. first day at school, first communion day, first time away. All these things trigger the raw grief I experienced at their birth. (Hannah).

Similarly, Heather describes how what should have been a happy occasion when her survivor was signed off by neonatal services; was bittersweet because it marked the loss of connection with individuals who had known her deceased twin:

I found myself getting really upset when my surviving twin was finally signed off from our consultant after two years of check-ups. Whilst I hated going back to the hospital our consultant was one of the few people who had met and cared for the son we lost. (Heather).

Coping strategies were individualised, but most mothers found ways to incorporate both twins at milestones in ways that were comfortable for them:

We have agreed that the twins' birthday will always be a date for celebration for Daisy, and that we will have a separate day to celebrate Poppy's life. We feel that Daisy is entitled to celebrate her birthday like any normal 4 year old. (Hannah).

Such moments are accompanied by a fleeting sense of overwhelming sadness and a glimpse of a life of parenting twins that could have been:

As she has grown, James has always felt like a shadow. When I look at her, I have often wondered what it would have been like with two, and could see him beside her or rolling his eyes at her. From when she was sleeping in her cot to rolling about in the bath as a toddler. (Claire).

Changing sense of self

Loss of an expected self was distressing. The identity of a twin parent is unique and afforded a sense of awe by others. With additional scans and care, mothers expecting twins are typically more 'looked after' than mothers expecting singletons. Mothers' reality was substantially different to the identity of "twin parent" that they had anticipated throughout pregnancy. Loss of an elevated sense of specialness and 'maternal identity' was difficult for many. 'I grieved for myself, I wasn't that 'twin mummy' that I had been so excited about'. (Hayley).

The unique nature of losing a twin was something that mothers found difficult in relation to acknowledgment of their loss. Lack of acknowledgement by others was regarded as an act of forgetting the deceased child and for some, a perception that others felt their child's life was too brief to be worthy of acknowledgement. 'Because our daughter died before anybody else met her she is not thought about by other people and didn't 'exist' in their lives'. (Jane).

Participants also suggested that others did not mention the deceased twin to avoid causing distress, yet the lack of acknowledgement was itself distressing.

‘One well-meaning health visitor crossed out the "Twin One" heading on Olivia’s red book after noticing I was always being asked where my other twin was. She did it to try and protect me but I liked having it there because I do have twins’. (Laura).

Worse than a lack of acknowledgment were comments suggesting that the survival of one baby negated the sense of loss experienced, provoking anger at the lack of recognition of the lost child as a person in their own right. ‘While I understand that we are incredibly blessed to have our healthy survivor, 'lucky' is not a word I'd choose to describe the situation’. (Angela).

Discussion

This work is important as it considers a previously unreported experience of how mothers adapt to caring for a surviving child whilst grieving for a lost child. Running through maternal accounts was a sense of duality. Navigating their journey involved mothers balancing remembrance of the lost twin with celebration of the surviving twin. Integrating their twins into their identity as a parent and family helped mothers to accommodate their sense of loss. Developing successful strategies to manage their own reactions and expectations of others took time and practice, especially in the initial bereavement period. For some, this involved reminding others of the lost twin’s place in the family whilst others prioritised protecting their lost twin’s memory by selectively sharing them with others. This was tempered with the need to avoid overwhelming themselves and surviving children with a sense of guilt about the deceased twin.

Historically, it was considered important for an individual to disengage with the deceased in order to move on with their lives (Freud, Strachey, Freud, Strachey & Tyson, 1957; Bowlby, 1980). However, more recent bereavement theory suggests that continued integration of the individual within the lives of the surviving person is more common (Klass, Silverman & Nickman, 1996). This ability to continue the bonds with the deceased relies on the bereaved having experienced the opportunity to develop a relationship and shared history prior to death. For mothers and immediate family this was possible due to a developing relationship with the twins prior to birth, and in spending time with the deceased twin at time of death. Mothers and the immediate family had more time to create these shared memories than others and so the glances of what might have been were more pertinent to them. Resonant with continuing bonds theory (Klass et al., 1996), many mothers emphasised the importance of continuing to create a history of the child within their family.

Maternal experiences were bittersweet, incorporating joy associated with parenting a living child whilst grieving the loss of another. Drawing from the work of Hannum and Rubinstein (2016), we see that the imagined future and identity associated with being a parent of twins, and expectations of their children's development is challenged in a unique way. This differs from the experience of parents who grieve the loss of a singleton, where there is no physical reminder of the surviving child's development. This is not to say that losing a single child is less difficult, but twin loss brings distinct simultaneous challenges of parenting and grieving.

For mothers in this study, the challenge of an altered identity was difficult. They struggled to adjust from being a parent of twins to that of a singleton. This is similar to the identity and temporal challenges discussed in the chronic illness literature (Charmaz, 1983). The

experiences and meanings upon which these mothers had built their former positive self-images (mother of twins) were no longer available to them (Hannum & Rubinstein, 2016), and for some, this resulted in a diminished self-concept that impacted on their identity as a parent of twins.

Limitations and future research

This exploratory study of maternal accounts of single twin loss has enabled us to see how mothers sought to integrate the experience within their lives as they learnt to manage their own and others expectations. However, we acknowledge the lack of the fathers voice in this study and the ways in which fathers may process and experience their bereavement and identity in this situation. Future researchers might consider innovative ways to access this hard to reach group.

The mothers derived their own version of stock answers to frequently asked questions such as ‘how many children do you have?’ It would be useful for parents to have more access to others’ stories about how to handle this question to enable them to prepare themselves for this common inquiry.

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